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Case report

Cystic fibrosis: A balancing act?

Trudy Havermans *, Kris De Boeck

University Hospital Leuven, Belgium

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Abstract

Cystic fibrosis has evolved from an illness where children died in their teens to one with a longer life expectancy into adult life. Patients now usually keep themselves in a good physical condition, which gives them an opportunity to live a relatively 'normal' life. There is a catch: a patient can only achieve this by adhering to a strict, complex and time-consuming therapeutic schedule, thereby introducing an abnormal element into a 'normal' life.

In this paper we discuss the issue of balancing 'being ill' with 'living like healthy children', and argue that 'normality' is as crucial in any developing CF child as the 'permission' to be ill. An important question arises as a consequence of the major improvements in CF care, namely—'Should all care be done at home or are there advantages in doing part of it in hospital or clinic?' We contend that this is where the balance lies as there are advantages for some care to continue to be done in hospital.

When CF is diagnosed, especially if the situation is critical, it is devastating for most parents to realise their child has a life-long illness. Little balancing is possible at this stage as the scales are weighed down with CF. Parents say that they cannot think about anything else and they doubt whether they will ever be able to cope. Once the condition stabilizes, one observes a gradual adaptation to the illness because the integration of CF care into family life is essential. Of course there are families with poor adaptive skills, but the majority of families cope very well indeed. It is this group of families this paper addresses.

CF care entails several modalities of treatment ranging from taking enzymes, vitamins, medication and physiotherapy, to complying with dietary regimes, regulations and careful attention to hygiene, socializing, etc. CF has implications within the social context of a family: the nature of CF has to be communicated to brothers/sisters, the extended family, neighbours, friends and school, as well as a wider community of casual acquaintances. In spite of the extent of these interventions, a CF child's cognitive, social and emotional development is exactly the same as that of a healthy child. Once CF has become part of family life the balancing act starts between 'health and illness'.

A prime question for CF carers should be how they can help or advise parents and patients in this balancing act. By advocating a 'perfect' CF treatment plan, not taking into account family or patient characteristics, there is a risk of families and patients dropping out. By focussing on 'normality' alone there is the danger of failing to provide the best possible CF treatment.

The best way forward seems to be to try to integrate most CF care into the family, thereby giving patients the opportunity to carry out day-to-day CF treatment within the home, for example, performing physiotherapy independently in the home by teaching parents and/or the patient to use quality equipment and not to depend solely on physiotherapists. A CF team should actively search for ways and methods to make this possible, because, for example, it is not realistic for a family with three children to visit a physiotherapist daily, let alone twice daily. In other words, one should aim at integrating CF care within the routine of the family and not on an externally based routine. A consequence of taking this direction might be that there is less immediate control on how well physiotherapy is performed; but by spending more time on educating and

* Corresponding author.
E-mail address: trudy.havermans@uz.kuleuven.ac.be (T. Havermans).

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teaching patients at regular intervals and by careful monitoring it should be possible to ensure that there is no detriment to the child.

To come back to the 'balancing act', we also argue that at crucial times CF should be taken outside the home environment. It is deleterious to 'overbalance' in the direction of normality by performing *every* single part of treatment in the home. CF children are normal children with a serious illness. There is the hazard that awareness of this fact may not take place as effectively in the home as it would in hospital. For example, over the past 15 years home IV care has become part of CF treatment. There is an inclination towards providing home IV treatment to all patients and their parents. Several studies have addressed the treatment results comparing in-hospital to home IV treatment [1–4]. We would like to address an important contra-indication of home IV treatment: the provision of home IV therapy, away from the clinic, may result in CF being perceived as an ordinary illness, readily treatable at home, from which one can recover 'easily'. We believe normalization of CF in this way to be a dangerous trend. One could argue that this is somewhat patronising, but when a CF patient's condition is temporarily worse, or gradually worsening, it is imperative for patient and family to become familiar with hospitalization. In hospital, confrontation with the illness is inevitable, because of intensive treatment, but in this 'balancing act' it also gives an opportunity to realise what is involved in living with CF.

In conclusion, the achievements in lowering morbidity and in better survival in recent decades has postponed the moment at which CF starts to critically intervene with day-to-day life, with the result that nowadays children feel less different from their peers than CF children did some 20 years ago. When CF is stable it is a remarkable and good achievement to have integrated so much care into the home environment but, equally, when the illness becomes more problematic, there are major therapeutic, psychological and social advantages to in-hospital care.

We argue that CF teams should develop a vision for this issue and not just go with the flow of fashion. The choice between home and hospital care should be founded on a broader vision of CF care and based on the belief that 'habits' or 'pity' are bad advisors.

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